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The New Old Age - Avoiding the Call to Hospice

By PAULA SPAN

What if I told you about an organization you could call when your elderly parent became so seriously ill that it appeared unlikely she'd recover?

What if I told you that this organization would send well trained nurses to see your parent, aides to lend a hand with daily care, a social worker to help the family grapple with the emotional difficulties? That these folks would deliver equipment you might need — a hospital bed, say, or wheelchair — and all your parent's drugs? What if they'd also send a chaplain if you wanted one? And provide a nurse to call 24/7 when you had questions or problems? And volunteers who would stay with your parent while you took a few hours' break, even if just for a long, quiet walk?

And what if I told you all this would cost you nothing, that Medicare would pay for it all? You'd pick up the phone, right? It's what caregivers so often yearn for and so seldom can locate: expertise, compassion, *help* that they can afford.

Now, what if I told you this organization was a hospice?

You might still call — the proportion of American deaths involving hospice care is climbing steadily. In 1998, when my mother was a hospice patient, the figure was only 18 percent; [now it's nearly 40 percent \(PDF\)](#).

But even if you did call, odds are you'd have waited so long that the hospice team would have very little time to do what it's good at doing

— providing care and comfort to the dying and their families. My mother, diagnosed with uterine cancer, was in hospice care for three months, thankfully. Overall, though, the median length of stay in hospice is just 20 days, and almost a third of patients enroll a week or less before they die.

Yet in surveys after patients' deaths, more than 98 percent of family members say they would recommend hospice to others.

Why do people wait so long to call? Why let what's invariably a wrenching time be even harder than it has to be?

Sometimes, simple misconceptions are to blame. People may think of hospice as a place rather than a service that aims to let people die in their homes. (A few hospices also operate residences.) Or they think hospice is for cancer patients, though in fact the majority of those in hospice have other terminal illnesses.

Doctors may neglect to mention hospice care, or even discourage it. (Maybe you've heard the grim joke: Why are coffins nailed shut? To keep doctors from administering more chemotherapy.)

A [study released Monday by a Harvard Medical School team](#) found that about half of patients with metastasized lung cancer, the leading cancer killer, didn't discuss hospice care with their doctors within four to seven months of diagnosis. Yet the average post-diagnosis survival for metastatic lung cancer is just four to eight months.

Sometimes, though, it's families who don't want to hear the word hospice. They think it's giving in, relinquishing hope.

"Nobody wants to say yes to death," said Don Schumacher, president of the [National Hospice and Palliative Care Organization](#). "America is

a death-denying society, much more than others. And the health care system wants to continue to treat and treat and treat.”

So even if your physician will sign the form saying that in her best judgment, death is likely to occur within six months if the disease follows its normal course — and that’s all that’s needed to enroll in hospice — often it’s the children who can’t bear to acknowledge that a father probably won’t rebound this time, that a mother is dying.

So families wait. And the parent dies anyway — maybe in pain that could have been eased, maybe with fears that could have been assuaged or lessened had hospice workers been able to offer more than brief crisis management.

How much hospice care is optimal? Mr. Schumacher thinks three months. Regina Bodnar, director of clinical services at Gilchrist Hospice Care in Baltimore, would prefer six months. But the median stay for a patient in her hospice last year was just 16 days. By the time hospice workers gets a call, said Ms. Bodnar, “the patient and family have been going it alone for weeks and months.”

“They deserve much more attention and assistance,” she added.

It’s a pity, isn’t it? Eleven years later, I still remember my mother’s aide Terry, who sewed a small doughnut-like pillow to prevent pressure sores from developing on Mom’s ear as she spent more time in bed. I wouldn’t ever have thought of that, but I wasn’t a specialist in end-of-life care. I was just glad we’d reached out to people who were.

Paula Span is the author of “When the Time Comes: Families with Aging Parents Share Their Struggles and Solutions,” to be published next month by Grand Central Publishing.